

SPEAKER PROFILES

*** Alphabetized by first names ***

Adrienne Shapiro

Co-founder, Axis Advocacy

Adrienne@axisadvocacy.org

Adrienne Shapiro is co-founder and Science Administrator of Axis Advocacy, supporting work to cure Sickle Cell Disease. Adrienne is a fourth generation of mothers in her family to have a child born with Sickle Cell Disease, and was an early supporter of work with bone marrow transplants and later stem cell research. She speaks nationally and internationally at educational conferences. For more information visit www.axisadvocacy.org

Alesia Evans Wardlow

Alesia is a parent and caregiver of a sickle cell warrior. Her hope is that through sharing my caregiver experiences, other caregivers and warriors will be more prepared to meet the challenges of transitioning into the world of adult health care and managing sickle cell disease.

Alexis J Wardlow

Chef & E-Nutritionist, Le Cordon Bleu

ajwardlow@yahoo.com

Facebook.com/DansIsMyLyfee

Alexis Wardlow is a Warrior living with Sickle Cell Anemia SS. Although she has struggled with sickle cell, as well as two other chronic conditions (Crohn's Disease and Primary Sclerosing Cholangitis), she manages her diet, nutrition, and exercise in moderation, and it has made her life much easier. She's been afforded the opportunities of graduating with her culinary degree, working with different celebrities all over southern California, and is also going back to work on attaining her Nutritional Science and Psychology Degree to do work in the medical field working with people like herself. With these experiences from personal goals, as well as with her medical situation, she hopes to encourage people to keep going with anything they feel they can do because it is possible. She is convicted that everyone can make a difference!

Brian R. Robinson, MD

Vice President, Medical Affairs

Bluebird Bio

Brian Robinson joined bluebird bio in June 2015 to lead the Medical Affairs function. He is responsible for driving medical strategies and tactics that support successful product development and guide education, research and communication about bluebird bio's innovative therapies. His team works with numerous stakeholders, including physicians, scientists, advocates, patients, and caregivers. Dr. Robinson has over 12 years of experience in biotechnology Medical Affairs. Most recently, he was the Global Medical Lead for the hemophilia program at Biogen. Prior to Biogen, Dr. Robinson held similar Medical Affairs roles

at GE Healthcare, Pfizer, and Abbott Laboratories. Before joining the drug development industry, he engaged in basic science and clinical research at Harvard University and MIT. Dr. Robinson completed an internship in surgery and subsequent training in otolaryngology at the Tufts New England Medical Center. He received a B.A. in anthropology from Yale University and a Doctorate of Medicine from Tufts University School of Medicine.

Cassandra Trimnell, BS

President, Founder, Sickle Cell 101

ctrinnell@sc101.org

As Founder and President of Sickle Cell 101, Cassandra is an active educator and advocate within the sickle cell community. Her passion for sickle cell stems directly from her living with the disease, hgb SS. Cassandra received a B.A. in Global Studies: Social, Political, and Economic Development from Sonoma State University. In 2014, Cassandra received her sickle cell education certificate, issued by the Department of Public Health. Cassandra is responsible for developing and creating the educational material and curriculum presented by Sickle Cell 101. As a sickle cell educator, Cassandra provides education and awareness through social media platforms such as Instagram, Facebook and Twitter. Other education platforms include community settings such as: Continuing Education Unit trainings for healthcare professionals, health fairs, sickle cell camp kids and teens, and events. Cassandra also volunteers for various sickle cell organizations.

Charles Jonassaint, PhD, MHS

University of Pittsburg, Dept. of Medicine

@c_jonassaint

Dr. Charles Jonassaint is a practicing clinical health psychologist with an MHS in cardiovascular epidemiology focusing on behavioral medicine and health services research. He has clinical expertise in chronic disease self-management and cognitive behavioral therapy intervention and has had extensive experience working with patients who have sickle cell disease. He completed his graduate training at Duke University and medical psychology residency at the Duke University Medical Center. He went on to do a clinical research fellowship at Johns Hopkins University School of Medicine, as well as, a Masters in Epidemiology at the Johns Hopkins Bloomberg School of Public Health. He is currently funded through an AHRQ PCOR K12 grant to lead a program of research in sickle cell disease focused on designing, cost-effective, scalable, mobile technology-delivered, stress and pain management interventions that patients can easily access on their own mobile phones or tablets.

Coretta Jenerette, PhD, RN, CNE

Associate Professor, School of Nursing

University of North Carolina

@DrCJen

Dr. Jenerette earned a PhD and MSN in nursing from the University of South Carolina and her BSN from Clemson University. She completed a certificate in nursing education at The

University of North Carolina at Chapel Hill and is a certified nurse educator. She also completed post-doctoral fellowships at both Yale University and The University of North Carolina at Chapel Hill. Her program of research is aimed at enhancing self-care and family management in vulnerable populations with a focus on individuals with sickle cell disease. She uses both qualitative and quantitative methods to identify vulnerability factors in order to intervene by enhancing self-care and family management resources with the goal of improved health outcomes. Her current projects include (1) improving communication between patients and providers, especially about pain, by teaching skills to patients in ways that enrich the patient-provider relationship; and (2) using a dyadic approach in adolescents with sickle cell disease and their mothers in an exploratory study over 5 web-based sessions to cultivate informed, activated, adolescents living with sickle cell. Dr. Jenerette is the immediate past president of the International Association of Sickle Cell Nurses and Physician Assistants.

Diana Ross, MSN, RN

Research Coordinator

Emory University

Diana.ross@emory.edu

Over 30 years experience as a registered nurse with 10 years experience in research and 5 years experience working with the sickle cell population.

Gary A. Gibson

President/CEO, Martin Center Sickle Cell Initiative

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Gary A. Gibson has enjoyed a distinguished career that features significant positions of authority in the private, public and nonprofit sectors. Currently serving as the President and Chief Executive Officer of Martin Center, Inc., Gary is responsible for leading Indiana's only not-for-profit agency dedicated to Sickle Cell Disease. Under his leadership, Martin Center provides support services to individuals with Sickle Cell Disease and Sickle Cell Trait, provides Sickle Cell education to the community and advocates on behalf of those who must live with the disease. Gary's passion for helping those with Sickle Cell has its roots in his previous life and marriage to a Sickle Cell patient who passed away at the age of 36 due to complications from the disease.

Gary is the host of the Sickle Cell Action Network Internet Radio Show, a weekly show that educates, empowers and informs the public about the continuing effort to eradicate Sickle Cell and to support those living with it.

He has published two white papers on Sickle Cell, "Sickle Cell Disease: Still Here and Still Causing Pain" and "Sickle Cell Disease: The Ultimate Health Disparity." He also has successfully worked with the Indiana State Legislature since 2013, work that has led to a doubling of the state's budget for Sickle Cell services. In April 2016, Gary worked with the Centers for Disease Control and Prevention to present the "Town Hall Meeting on Sickle Cell Disease Featuring the CDC," the first event of its kind in Indiana's history.

Prior to joining Martin Center, Gary served in leadership positions at the Indiana Bureau of Motor Vehicles, the Indiana Governor's Office, the Indiana Department of Administration and the Indianapolis Airport Authority. He also spent several years as CEO of an economic development consulting company, Gibson & Associates, LLC.

Governor Evan Bayh presented Mr. Gibson with the state's highest honor, the Sagamore of the Wabash, in January 1997. Governor Frank O'Bannon presented him with another Sagamore in January 2001.

In 2004, Gary published an inspirational science fiction novel called *New Earth Rising*, a fictional novel about extraterrestrials who come to Earth to show its inhabitants the way to a new reality of equality, peace and spiritual growth.

Mr. Gibson is committed to making a difference in his community. He has served in leadership positions on numerous boards and commissions, including the Martin University Board of Trustees, the Governor's Commission for Minority and Women's Business Development, the City of Indianapolis/Marion County Equal Opportunity Advisory Board, Martin Center and the ACE Mentor Program of Indiana.

Gary currently resides in Indianapolis, Indiana.

Helen Sarpong

sarponghelen@gmail.com

Helen Sarpong is currently a patient advocate and healthcare educational public speaker for Sickle Cell Disease. She was born with Hemoglobin SS and she has spent her life struggling to navigate the healthcare system, as well as to take back control of her life away from the painful cycles of the disease. She is a mother of twin girls and she has been promoting Sickle Cell Awareness to patients and their families, resident medical students, biotech and pharmaceutical companies for the past six years. Recently, she has partnered with the Greater Boston Sickle Cell Disease Association (GBSCDA) to help reach out to the local community.

Ify Osunkwo, MD, MPH

Medical Director, Adult Sickle Cell Program

Carolinas Healthcare System

Levine Cancer Institute and Associate Professor

University of North Carolina at Chapel Hill

Dr. Ify Osunkwo, a specialist in hematology and Sickle Cell Disease at Levine Cancer Institute in Carolinas HealthCare System (Charlotte NC), had made it her mission to improve the quality of life for Sickle Cell patients. After obtaining her medical degree from the University of Nigeria, she obtained a Masters in Public Health from Johns Hopkins University in Baltimore, MD and completed a fellowship in Pediatric Hematology/Oncology at Columbia University in New York, NY. With over two decades of clinical experience in sickle cell disease, Dr. Ify leads the Transition/Care Coordination working for the South Eastern Regional Genetics Collaborative, and serves as the Secretary for the National Sickle Cell Adult Provider Network. She currently leads a team of dedicated and passionate providers and staff striving to establish a

comprehensive, multi-disciplinary system of care for all adults living with SCD in the Charlotte Metro area, approximately 1300 individuals served by Carolinas Healthcare System. This care model involves critical components such as the prominent role of the PCP, multi-faceted care navigation, case management and community support networks and is guided by a robust Community Advisory Board and system led Oversight Committee. Dr. Ify believes strongly that knowledge is power and her team offers quarterly patient education sessions for adults with SCD to enhance their health literacy and self advocacy skills and better understand treatments offered to improve their quality of life

Jew-EL Darbone

#Boldlipsforsicklecell

Co-Founder, CFO

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Jew-EL Darbone is one of the founders of #Boldlipsforsicklecell and its CFO. She is a social media maven and sickle cell advocacy and empowerment is her passion. A graduate of Mount Tabor High School in Winston Salem NC she doesn't allow any obstacle to stop her from living life to the fullest.

Judy Gray Johnson, B.S., M.Ed.

Sickle Cell Educational Resources, Inc.

www.scerinc.org

Judy Johnson has been living with Sickle Cell for more than 70 years. She is a retired teacher of almost 40 years. While she grew up in Virginia and South Caroline, she currently reside in Valencia, California and continues to advocate in the cause of finding real quality of life changes for those suffering with Sickle Cell.

Julie Kanter, MD

Medical University of South Carolina

Director of Lifespan Comprehensive Sickle Cell Center

@jkw4444

Kimberly Monique Davis

Administrative Coordinator

Sickle Cell Community Consortium

As Founder and President of Sickle Cell 101, Cassandra is an active educator and advocate within the sickle cell community. Her passion for sickle cell stems directly from her living with the disease, hgb SS. Cassandra received a B.A. in Global Studies: Social, Political, and Economic Development from Sonoma State University. In 2014, Cassandra received her sickle cell education certificate, issued by the Department of Public Health. Cassandra is responsible for developing and creating the educational material and curriculum presented by Sickle Cell

101. As a sickle cell educator, Cassandra provides education and awareness through social media platforms such as Instagram, Facebook and Twitter. Other education platforms include community settings such as: Continuing Education Unit trainings for healthcare professionals, health fairs, sickle cell camp kids and teens, and events. Cassandra also volunteers for various sickle cell organizations.

Kirshma Khemani, MD

Emory University

AFLAC Cancer and Blood disorders center-Pediatric Bone Marrow Transplant Division

Lakiea Bailey, Ph.D.

Executive Director, Sickle Cell Community Consortium

Dr. Lakiea Bailey is a sickle cell disease advocate, educator and research scientist. Diagnosed with sickle cell disease at age three, she has become a passionate advocate for those living with rare diseases and is committed to serving as a voice of encouragement and empowerment within the sickle cell community.

Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor degree in Biochemistry and Molecular Biology in 2001 and a Doctorate degree in Molecular Hematology and Regenerative Medicine in 2012. During the course of her education, Dr. Bailey was named a Southern Regional Education Board (SREB) Doctoral Scholar, was the recipient of multiple honors and awards, including the Fisher Scientific Award for Overall Excellence in Biomedical Research, the Medical College of Georgia Alumni Association Award, the Georgia Regents University Leadership Award and was inducted in the Alpha Upsilon Phi honor society. Dr. Bailey is the Executive Director of the Sickle Cell Community Consortium, a coordinated network of sickle cell disease community-based organizations throughout the United States, a contract consultant with bluebird bio, has served on patient panels or disease expert with Pfizer, Novartis, FDA, NHLBI and sits on the Research Advisory Board for the Foundation for Sickle Cell Disease Research.

Mattie Robinson, MS, MA

Mattie's professional background includes over 7 years of experience in biomedical research and education. As a scientific researcher, Ms. Robinson worked to develop future treatments for Sickle Cell Disease and related blood disorders. In 2013 she hung up her lab coat and began a rewarding career in nonprofit management, advocating for the rights and needs of people living with the disease. She holds graduate degrees in Microbiology and Cell Science from the University of Florida as well as Human Genetics and Molecular Biology from the Johns Hopkins School of Medicine. Her passion is to teach everyone to understand the elegant intricacies of science and medicine.

Shamonica Wiggins

#BoldLipsForSickleCell

Co-Founder, CEO

Shamonica Wiggins is a 27 years old and I have Sickle Cell SS. She was diagnosed at 2 weeks of age. After high school she attended Texas Tech University pursuing a degree in Newspaper-Editorial Journalism. Growing up as a Dallas native her family and medical team never told me I could not do something, so I have always striven to be the best I can be. That is not a luxury that every Sickle Cell Warrior is told, so that has always driven me to inspire others like me. That drive is what lead to the founding of #BoldLipsForSickleCell in 2014. Being the CEO of this amazing organization is something I am very proud of. Me, Jew-El Darbone and the Bold Lips team have worked very hard to become an official 501C(3) Non Profit. Speaking about this disorder and spreading Sickle Cell awareness is my passion. It brings me so much joy being an inspiration to warriors both young and old. Life with this illness is not always easy but living it to the fullest is worth all the hardships we face. This life is a gift and I cherish it daily. Being a patient speaker on the Mental Health Panel means a lot to me. Anxiety and depression really set in for me during college but thankfully I was able to seek help coping with these issues. Now as a patient at the UT Southwestern Comprehensive Sickle Cell Clinic seeing a psychiatrist is part of my care plan and I feel I have greatly benefited from this. I am hoping to show others that we all can reach that light at the end of the tunnel.

Shirley Miller, MA

Carolinas Healthcare System

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Tandua Washington, MD

TSPMG, General Pediatrician

[Facebook.com/doctwash](https://www.facebook.com/doctwash)

Dr. Tandua Washington is a General Pediatrician in the Atlanta area who has Sickle Cell Disease. A New York native, Dr. Washington graduated Hofstra University with a BS in Biology. She graduated from the Medical College of Virginia with honors and completed her residency at Albert Einstein Medical Center in Philadelphia. She has been practicing Pediatrics for 16 years, with a special interest in caring for children with Sickle Cell. She has received many awards and accolades for her achievements in her field. Dr. Washington is married and has 2 sons who also have Sickle Cell Disease. The family is very committed to advocacy work in the Sickle Cell Community.

Tosin Ola, RN, BSN

Founder & President, [Sickle Cell Warriors](#), Inc.

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Tosin Ola, BSN, RN knows firsthand the challenges of living with sickle cell disease. The practicing registered nurse and mother of twin toddlers, launched the Sickle Cell Blog in 2007 to bond with others and share her experience living with this debilitating and deadly disease.

A short two years later, the sickle cell advocate created an online platform – the Sickle Cell Warriors website – to broaden the discussion and give the community a much-needed voice. The educational site is designed to raise awareness of this complex chronic medical condition, address the serious complications of the disease, provide expert advice and research news, promote local events and much more. Also, the portal highlights “Warriors in the Spotlight” - people living with sickle cell disease who share their personal experiences and are a source of inspiration for others.

To complement those efforts, Tosin’s Sickle Cell Warriors Facebook Page supports and encourages members to engage with others going through the same daily struggles. The leading social media channel has connected over 18,000 members, making it the largest online group of people affected by this disease.

Tosin strives to create a community where people can feel comfortable asking (and getting answers to), their most pertinent and personal questions related to sickle cell disease. There has not been a topic that Tosin shies away from or is afraid to address. She is dedicated to presenting positive and uplifting messages about sickle cell to the society, as well as empowering sickle cell patients to take control of their disease and think differently about life with sickle cell. She believes that sickle cell does not define you, and that one can have a beautiful and fulfilling life regardless of sickle cell. Tosin has partnered with Mast Therapeutics as a Corporate Liaison to lend her expertise, provide valuable insight and counsel the company from the disease patient and advocacy perspective.

With an Associate’s Degree in Nursing (Oakwood University) and a Bachelor’s Degree in Nursing (University of Phoenix), she is working on her Master’s Degree in Nursing and Business Administration with an emphasis in Healthcare Management. She serves as an authoritative speaker, and reliable source to both media and book authors. Tosin lives in Carlsbad, California with her toddler twins and husband. Visit the Sickle Cell Warriors website, or email Tosin directly Tosin@SickleCellWarriors.com or SickleCellWarrior@gmail.com

Trevor Thompson, Ed.D.

CEO, Sickle Cell Foundation of Tennessee
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Dr. Trevor Kennebrew Thompson is the Founder/CEO of the Sickle Cell Foundation of Tennessee (SCFT). The mission of the foundation is to provide comprehensive services to individuals living with Sickle Cell in Tennessee and the Mid-South community. The vision of the foundation is to increase the education, health awareness and life skills of individuals living with Sickle Cell Disease to be more self-sufficient and to improve their quality of life. SCFT is responsible for providing comprehensive social services to meet the unmet needs of individuals living with Sickle Cell in the Mid-South (East Arkansas & North Mississippi) and the State of Tennessee. SCFT works diligently to eliminate the stigma that is associated to individuals living Sickle Cell Disease (SCD) and empower them to make a difference through acquired knowledge and skills.

Dr. Thompson has Sickle Cell Disease and through his work he has developed a sincere understanding toward the problems that the consumers face day to day. However, he does not

believe in excuses. He serves as an ambassador for the Mid-South Sickle Cell community and as Chairman of the Diggs Kraus Sickle Cell Clinic advisory council he logged more than 34,000 volunteer hours and led efforts to raise approximately \$500,000 during his tenure. He states that “the disease may have my body, but not my spirit” and lives by the family motto “DUM SPIRO SPERO” which is Latin for “While I Breathe, I Hope.”

Velvet Brown-Watts, MSW, CM

Supporters of Families with Sickle Cell Disease, Inc.
Chairperson
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Yvonne M. Carroll, RN, JD

President, International Assoc. of Sickle Cell Nurses and Physician Assistants
Director, Patient Services
Dept. of Hematology
St. Jude Children’s Research Hospital
Yvonne.carroll@stjude.org

Yvonne M. Carroll, RN, JD is the Director of Patient Services in the Department of Hematology at St. Jude Children’s Research Hospital. Yvonne graduated with a Bachelors of Nursing Degree from the University of Tennessee and a Law degree from the University of Cincinnati. Yvonne served in the United States Navy as a Staff Judge Advocate. She joined SJCRH in 1999 in the Department of Hematology and served in several positions before becoming the Director of Patient Services. Yvonne is active in Hematology and the sickle cell disease community and serves on the Governor’s Genetic Advisory Committee for the State of TN and as President of the International Association of Sickle Cell Nurses and Physician Assistants (IASCNAPA). Throughout the years, Yvonne has been a Principal Investigator and Program Manager on numerous sickle cell related grants and has spoken locally, regionally, and nationally on sickle cell disease and trait. Yvonne has developed partnerships with numerous community organizations and rural healthcare workers to improve awareness and treatment for people with sickle cell disease.